

Succession Planning in Uganda: Early Outreach for AIDS-Affected Children and Their Families

RESEARCH SUMMARY

Uganda has been widely recognized for lowering HIV incidence (Asimwe-Okiror et al. 1997; Hogle 2002). However, because so many adults were previously infected and given the long period between HIV infection and death from AIDS, the number of orphaned children is still rising. By the end of 2001, there were 880,000 children under the age of 15 living in Uganda who had lost one or both parents to HIV/AIDS (UNAIDS 2002).

But these orphans represent only the tip of the iceberg, since there are many more vulnerable children whose parents are alive but living with HIV infection. Evidence suggests that the negative impacts of HIV/AIDS affect children long before parents die, beginning when a parent's health starts to decline (Gilborn et al. 2001). Yet few programs exist to help families before a parent's death, and there is little research on the effectiveness of existing programs for AIDS-affected children.



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Boy in Tororo with the aunt who takes care of him. The aunt's own children are in the background.

Study Methods

In 1999, Makerere University and Horizons initiated a study in the Luwero and Tororo districts of Uganda, largely rural districts with small urban and peri-urban populations. The primary objective was to assess the outcomes of two different yet complementary programs being implemented by the Ugandan office of Plan, an international NGO: succession planning (SP) and orphan support (OS).

Table 1 Characteristics of succession planning

Target groups	<ul style="list-style-type: none"> ● HIV-positive parents ● Their children ● Standby guardians
Program components ¹	<ul style="list-style-type: none"> ● Counseling for HIV+ parents on serostatus disclosure to children ● Creation of "memory books" ● Support in appointing standby guardians ● Legal literacy and will writing ● Assistance with school fees and supplies ● Income-generation training and seed money ● Training for standby guardians ● Community sensitization on needs of AIDS-affected children

¹ Most participants received only selected components.

SP reaches HIV-positive parents, their children, and standby guardians while the family is still in a position to plan for the children's future (see Table 1). OS serves only orphaned children and their guardians. Together, the programs form part of a continuum of care for AIDS-affected children that starts at the time of parental diagnosis or onset of illness and continues through orphanhood (Figure 1).

This summary describes the effects of the SP program on the actions taken by HIV-positive parents and standby guardians to plan and provide for the future of their children. To assess program effects, the researchers compared data from parents and standby guardians exposed to the SP intervention to a comparison group of parents who did not receive any OS or SP services. A subsequent publication will examine the effects of the OS program.

Researchers conducted structured interviews with HIV-positive parents, standby guardians, and children from both study groups at baseline and two years later. At each round of interviews, all adult clients of Plan Uganda's existing services for people living with HIV/AIDS (PLHA) (e.g., clinic- and home-based care) in the study areas were invited to participate and identify up to two

of their children and one standby guardian to participate in the research.

Researchers also carried out in-depth interviews and focus group discussions with counseling aides and parents to further explore key issues. Counseling aides train, support, and assist parents in all aspects of succession planning. In addition, data interpretation workshops were held in the study communities after the first and final rounds of data collection. Counseling aides, program participants, local NGOs, government officials, and other local leaders participated. Their insights about and interpretations of the data are incorporated into this analysis.

Table 2 shows the number of respondents and selected characteristics in the cross-sectional samples for the baseline and final interviews used for the SP evaluation. The vast majority of the parent respondents were female and had lost a spouse. Within the baseline and final rounds of data collection there were no statistically significant differences between the study groups in average age, sex distribution, or marital status of the parents. Compared to the parents, a greater proportion of the standby guardians were male and currently married (44 to 75 percent).

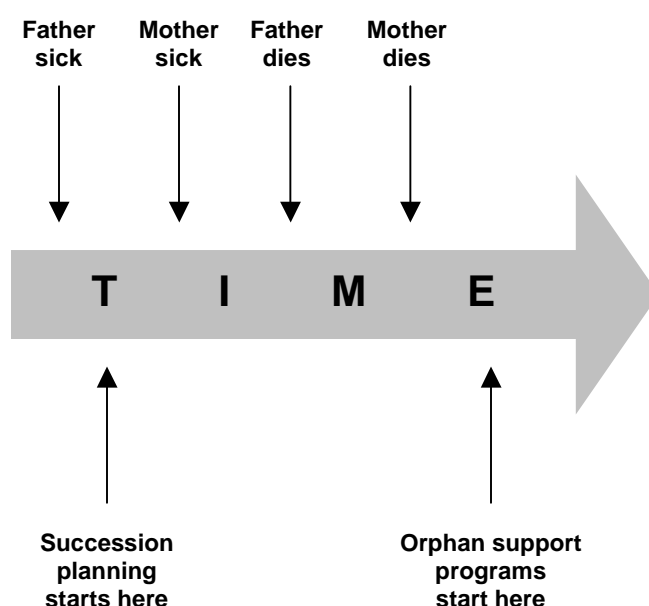
Figure 1 Continuum of care for AIDS-affected children

Table 2 Characteristics of the study populations

	1999 Interview		2001 Interview	
	Succession planning group	Comparison group	Succession planning group	Comparison group
Parents	n = 163	n = 103	n = 162	n = 118
Mean age (yrs)	38	36	37	38
Age range (yrs)	22-66	21-69	24-58	21-59
Female (%)	72	79	82	86
Widowed (%)	65	68	78	80
Standby guardians	n = 56	n = 28	n = 54	n = 20
Mean age (yrs)	39	37	39	37
Age range (yrs)	19-77	16-80	19-71	19-70
Female (%)	37	50	41	30
Married (%)	67	44	59	75
Older children (age 13-19)	n = 89	n = 53	n = 88	n = 57
Female (%)	44	57	48	41

Key Findings

The proportion of HIV-positive parents who appointed a guardian increased significantly after exposure to the SP program.

Only about half (53 percent) of HIV-positive parents in both study groups combined had appointed a guardian at baseline. Parents reported a number of reasons, such as not knowing anyone willing or able to be a guardian, still being in good health themselves, and not wanting to reveal their serostatus to a potential guardian.

Once the SP intervention was under way, counseling aides in the SP area reported that parents responded very positively to encouragement to appoint guardians. Indeed, there was a significant increase from 56 to 81 percent ($p < 0.05$) in the proportion of SP parents who had appointed a standby guardian (Figure 2).

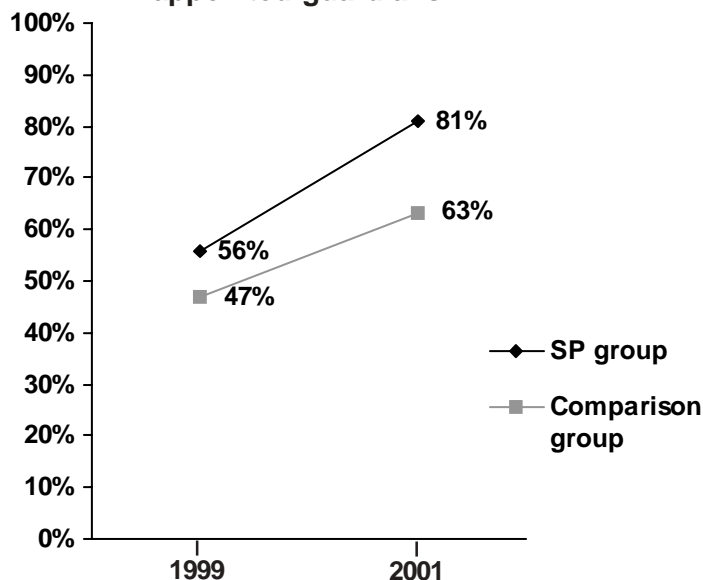
There was also a significant increase in the comparison group, from 47 percent to 63 percent ($p < 0.05$). However, given that there was not a statistically significant difference between the two groups at baseline (47 percent vs. 56 percent; NS) and that there was a significant difference between the two groups at the final

survey (63 percent of comparison parents vs. 81 percent of SP parents, $p < 0.05$), researchers concluded that exposure to the SP program is associated with a greater increase in the appointment of guardians. This finding was found to be true after controlling for age, education level, religion, gender, time since HIV diagnosis, time widowed, and district in a multivariate regression model.

After two years in the SP program, parents were significantly more likely to have disclosed their positive serostatus to at least one child.

Among orphans aged 13 to 19 years interviewed at baseline who knew that a parent had died of AIDS ($n = 40$), 85 percent believed that parents should disclose their serostatus to their children. Although 72 percent of parents reported that they were in favor of disclosing their HIV status to their children, the majority (53 percent of all parents) had *not* done so, often due to uncertainty about how to discuss the topic. Parents and children in favor of disclosure supported it because they valued honesty, talking about how the child could take precautions against HIV infection, and being able to plan for the future.

Figure 2 Percentage of HIV-positive parents who appointed guardians



In planning for their children's future, many HIV-positive parents realize they have to explain their health situation to family members and need help to do so. Therefore, the SP program facilitates and supports (although does not require) the disclosure process through group counseling, one-on-one support, and the creation of memory books.

There were significant increases in the proportion of parents who had verbally disclosed to a child in both groups (51 percent to 75 percent in SP, $p < 0.05$, and 40 percent to 59 percent in the comparison group, $p < 0.05$) (Figure 3). While there was no statistically significant difference between the two groups at baseline, there was at the time of the final survey (75 percent of SP parents vs. 59 percent of comparison parents, $p < 0.05$), suggesting that the SP program had a greater impact on parental disclosure to children. This finding remained true after controlling in a multivariate regression model for parent's age, education level, religion, gender, time since HIV diagnosis, time widowed, and district.

Most parents in the SP group (13 of 16) who participated in in-depth interviews at the end of the project had disclosed their serostatus to at least one child. Parents usually chose to disclose to children considered mature and able to keep

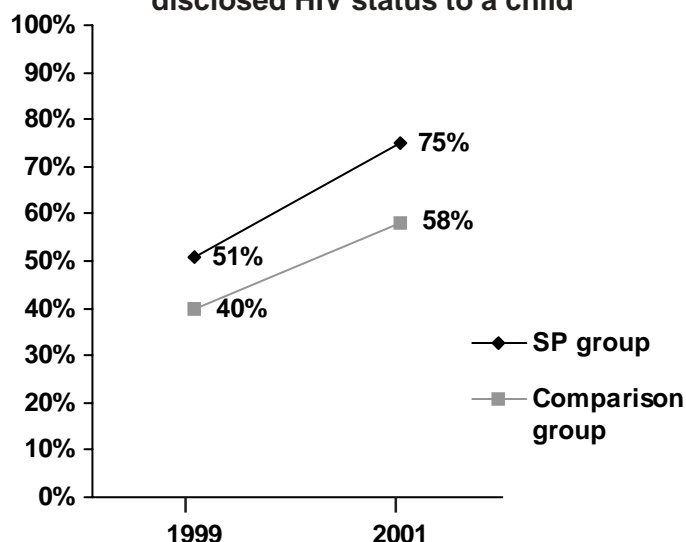
this information secret. Counseling aides and parents alike agreed that disclosure can be appropriate for children over 12, but not for younger children.

Reasons given by parents for disclosing to their children included wanting to help them prepare for the future, to discuss familial property, and to seek the children's assistance during times of parental illness. During in-depth interviews, all parents (16 of 16) stated that disclosure can strengthen family bonds and encourage children to take precautions against HIV/AIDS. However, learning that a parent is HIV-positive is never easy, even for children who go on to adapt well. Unfortunately, some parents reported that their children ran away from home (3 of 16) or reacted violently (1 of 16). Thus there may be a need for greater guidance to parents before deciding whether or not to disclose and for ongoing support to children who find out their parents' status.

Will writing doubled in both groups, but still only a small proportion of parents had written wills.

A striking finding at baseline was that many parents feared that, when they died, their property would be taken from surviving family

Figure 3 Percentage of HIV-positive parents who disclosed HIV status to a child



members by non-heirs (community members or relatives). Almost a third (31 percent) of widowed females had themselves experienced property grabbing (compared to only 5 percent of male widowers). Meanwhile, only 23 percent of all respondents had made *any* arrangements for inheritance of their property, and only 9 percent of parents had written a will. Legal training and will writing were then introduced as part of SP.

In each group, the proportion of parents who had written wills doubled from about one in ten (9 percent SP, 10 percent comparison group) at baseline to about one in five (20 percent SP, 21 percent comparison group) at the final interview. The change over time was significant ($p < 0.05$) in both groups, but there were no differences between groups at either baseline or at the final interview. Nor were there within-round differences in the proportions who had appointed executors (47 percent of parents in SP and 37 percent of comparison parents at final round of interviews, NS) or in knowledge of women's and children's property rights.

Qualitative data collected from counseling aides and parents from SP sites highlight the formidable fears and cultural obstacles faced by the program in trying to introduce will writing (see sidebar). Although there are written laws protecting the rights of women and children to a portion of familial property, customary or traditional law prevails in most of Uganda.

Despite these barriers, qualitative research revealed considerable interest and confidence in the value of wills among parents in the SP group, with many reporting that they had written wills as a *direct* result of program involvement (26 of 69 women and 17 of 32 men in the focus group discussions).

Sub-group analysis of the quantitative data reveal that within the SP group, respondents who

Horizons conducts global operations research to improve HIV/AIDS prevention, care, and support programs. Horizons is implemented by the Population Council in partnership with the International Center for Research on Women (ICRW), the Program for Appropriate Technology in Health (PATH), the International HIV/AIDS Alliance, Tulane University, Family Health International, and Johns Hopkins University.

reported attending the legal training component of the intervention were more likely to have written wills (25 percent vs. 12 percent, $p < 0.05$), to have an executor (54 percent vs. 38 percent, $p < 0.05$), and to have discussed property laws with their children (42 percent vs. 32 percent, NS). This suggests that there may have been a program effect for those exposed and that the findings on the larger group may have been diluted by the fact that not all parents received the legal component of the program.

Some focus group participants mentioned that they had heard of instances in which a will effectively protected a survivor's property rights, which in turn motivated more parents to write wills. Counseling aides predicted a change in practices would occur slowly but surely.

"Writing a will is one of the most difficult things a person can do in this culture. It is seen as bad luck, a final sacrament. Therefore a rise in will-writing will take place only gradually. People are now realizing the importance of wills."

Counseling aide in Luwero

Challenges to Will Writing in Uganda

- Widespread belief that wills and "preparing for death" will cause death.
- Traditionally, property is distributed only posthumously, by clan leaders.
- Traditionally, women and young children do not own or inherit property.
- Traditionally, wills are verbal, not written.
- Poor knowledge and enforcement of laws protecting women and children.
- Low literacy.
- Limited experience with legal issues among NGOs in rural areas.

Counseling aides observed that there was a need to increase will writing among men, whose participation had been limited but is critical to the preservation of familial property. Indeed, male participation in the entire SP program was low compared to that of females. They also reported that wills were more effective when the survivors were adults or older children, and far less so when the survivors were young children. A strong recommendation from many counseling aides and parents alike was to increase community sensitization and to involve local religious, clan, and government leaders in upholding property rights.

Standby guardians appointed by parents are predominantly male, but it is women who ultimately assume much of the responsibility for orphaned children.

The research team was only able to contact and interview a limited number of standby guardians because some parents had not yet identified one and because many appointed guardians lived outside the study area. At baseline, the standby guardians were predominantly grandparents, aunts, and uncles. Many of the standby guardians were already taking care of children who were

not biologically their own (55 percent of those in SP and 43 percent in the comparison group). This raises serious issues about the capacity of this group to take responsibility for more dependents and about the weakening of the social safety net for AIDS-affected children in the study areas.

More than half (57 percent) of the parents at baseline who had appointed a standby guardian chose a male. Yet, nearly two-thirds (63 percent) of *current* guardians (i.e., already caring for orphaned children) who were interviewed at baseline as part of the larger study were female (see Gilborn et al. 2001).

This seeming contradiction was explored in the data interpretation meetings with counseling aides, who explained that males, being wage-earners, are the parents' ideal providers, but that some males appointed as standby guardians are motivated by the prospect of material gain (of parental property or, in the case of girl orphans, bride-price). In some instances, after male standby guardians have taken what they can or discovered there is little to be gained materially, they shirk their responsibilities. In those cases, according to counseling aides, it is the women who take the children in.



Boy in Luwero with his maternal and paternal grandmothers who share responsibility for his care.

Overall, there was little change as a result of the program with respect to the attitudes and behaviors of standby guardians exposed to SP. Indeed the program offered limited opportunities for participation by standby guardians and did not appear to have substantial impact on the small sample interviewed.

SP principles “spilled over” into neighboring communities, suggesting widespread acceptability of SP services.

After preliminary data analysis, the research team was puzzled to find that improvements in some outcome variables directly related to the SP program were also found among the comparison group (although often to a lesser degree of magnitude). This unexpected finding was discussed with counseling aides at data interpretation meetings. They explained that news of the SP program had spread across the boundaries of the study areas and that neighboring communities were demanding the same services. Because some of the same organizations and counseling aides work in both study areas, it is possible that they responded to this demand in an *ad hoc* fashion. This “spillover effect” limits the study’s capacity to deduce statistical inference about the program’s effects. However, it may also be a testimony to the SP program’s appeal and acceptability.

What about the children?

The ultimate goal of SP is to ensure a better *future* for children whose parents are HIV-positive. A two-year study is not sufficient to assess the long-term effects of SP on children once they are actually orphaned. For this reason, the current impact analysis focuses on steps taken by parents and standby guardians exposed to SP to increase the likelihood that AIDS-affected children are better prepared to face the future. Perhaps one of the most important effects of SP occurred among older children, who generally expressed a desire for parents to be open with them about the parents’ HIV-status. Between

1999 and 2001, there was a significant increase in the proportion of older children in the SP group who reported that a parent disclosed his/her status to them (35 vs. 57 percent; $p < 0.05$).

Conclusions


Findings from this study suggest that succession planning is a promising approach for increasing the extent to which HIV-positive parents take action to ensure a better future for their children, particularly in terms of appointing guardians and talking to their children about being HIV-positive.

Some aspects of the program, however, require strengthening or adaptation. There is a need to build support among community leaders and members for the protection of women and children’s inherited property and the use of written wills or an alternative mechanism to do so. More opportunities should be created for the participation of standby guardians in the entire SP program. Some parents in the program were offered income-generation activities, and there is room to expand this to standby guardians. Collaborative income-generating projects involving HIV-positive parents, children, and standby guardians would allow for bonding between children and future guardians and would provide the guardian with an ongoing source of income and thus an incentive and means to take care of the children in the future.

Ways of including distant standby guardians should also be explored. Many city dwellers return to their villages occasionally. Activities could be arranged during these visits. Program activities for children could be enriched. Most important, children need ongoing emotional support during the process of parent-to-child disclosure.

In general, there is a need to increase participation in the program by the community at large, by local leaders, and by men, who for cultural and other reasons have shown less interest in the program, either as parents or standby guardians.

Notes:

- NS = Not statistically significant
- Baseline data presented in this summary may differ slightly from those reported in the Baseline Report (Gilborn, et al. 2000). This is because a subset of the full sample was used to analyze the impact of SP, while the baseline report presented data from the full sample.
- The full study included three rounds of interviews at annual intervals (1999, 2000, 2001). Only the first and final round of data were used for the current analysis.
- The full study included three study arms in 1999 and 2000 (Succession Planning, Orphan Support, and control). In each arm, the sample included parents, children, standby guardians, children currently orphaned, and their grandparents. The control group was eliminated for ethical reasons in 2001, to allow Plan Uganda to begin offering services in that area. Thus only the SP and OS arms were included in 2001 and could be used for the current analysis of 1999 and 2001 data. In the absence of the “true control” group, a comparison group was derived as follows for the current analysis: parents, children and standby guardians in the OS arm who were not receiving OS (because there were no orphans in the household) or SP (because it was not being offered in that area). Since they were not receiving either intervention, they were used in this analysis as the comparison group. 

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